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## Health: support provided and received in advanced old age

### A five-year follow-up

#### Gesundheit, Unterstützung leisten und erhalten im höheren Lebensalter: Ein 5-Jahres-Follow-up

► **Abstract** While research focuses mainly on support provided to the elderly, this paper deals with the very old as a support provider to his family as much as a care recipient from both his family and a formal network. We hypothesize that elders with declining health will try to maintain the provision of services, even when they require and receive help.

A total of 340 octogenarians from the Swiss Interdisciplinary Longitudinal Study on the Oldest Old (SWILSOO) were interviewed up to five times over five years

(N = 1225 interviews). A multi-level model was applied to assess the effects of health, controlled for socio-demographic and family network variables, on the frequency of services that the old persons provided to their family and received from their family and formal networks. Health is operationalized in three statuses: ADL-dependent, ADL-independent frail, and robust.

While the recourse to the informal network increased progressively with the process of frailty, the recourse to the formal network drastically increased for ADL-dependent individuals. Being ADL-dependent seriously altered the capacity to provide services, but ADL-independent frail persons were providers with the same frequency as the robust oldest old, showing their ability to preserve a principle of reciprocity in their exchanges with their family network. This continuity of roles may help frail persons to maintain their self-esteem and well-being.

► **Key words** frailty – ADL-dependence – social support – longitudinal – oldest old

► **Zusammenfassung** Während sich die Forschung hauptsächlich mit der Unterstützung befasst, die älteren Personen zuteil wird, un-

tersucht diese Arbeit, wie Personen im höheren Lebensalter sowohl ihre Familie unterstützen, als auch von ihrer Familie und dem institutionellen Netzwerk Hilfe erhalten. Wir nehmen an, dass ältere Personen mit schwindender Gesundheit versuchen, eine unterstützende Tätigkeit aufrecht zu erhalten, auch wenn sie selber Unterstützung erhalten.

Dreihundertvierzig Hochaltrige der SWILSOO wurden bis zu 5-mal über den Zeitraum von 5 Jahren (N = 1225 Interviews) befragt. Mit Hilfe von Mehrebenenmodellen wurde der Einfluss des Gesundheitszustandes auf die Häufigkeit, mit der ältere Menschen Dienstleistungen für ihre Familie erbringen und von ihrer Familie und vom institutionellen Netzwerk erhalten, untersucht. Dabei wurde für soziodemographische und netzwerkbezogene Einflüsse kontrolliert. Gesundheit wurde in drei Stufen operationalisiert: ADL-abhängig, ADL-unabhängig und gebrechlich sowie rüstig.

Während die Suche nach Unterstützung beim informellen Netzwerk mit zunehmender Gebrechlichkeit progressiv anstieg, wurde das institutionelle Netzwerk besonders von ADL-abhängigen Individuen deutlich mehr beansprucht. ADL-Abhängigkeit schränkte die Fähigkeit Unterstützung zu leisten stark ein. ADL-

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unabhängige, gebrechliche Personen leisteten jedoch ebenso oft wie die rüstigen Älteren Hilfe und zeigten dadurch ihre Fähigkeit einen Grad an Reziprozität im Austausch mit ihrem familiä-

ren Netzwerk aufrechtzuerhalten. Kontinuität im Rollenerleben kann gebrechlichen Menschen im höheren Lebensalter helfen ihr Selbstwertgefühl und Wohlbefinden aufrecht zu erhalten.

► **Schlüsselwörter** Gebrechlichkeit – Abhängigkeit – Soziale Unterstützung – Längsschnittstudie – höheres Lebensalter

## Introduction

The majority of research devoted to social support in gerontology focuses on the support that old persons received. Indeed, the instrumental aid received from the social networks offers old people resources helping them to deal with the various events or disturbances occurring in their daily lives, particularly in the area of health. It helps them to cope with their physical and psychological problems and consequently plays an important role in adjustment to the challenges of old age. The instrumental aid is provided mainly by the family network in the event of functional incapacity [3]. When that aid is insufficient or too specific, an old person may have recourse to the aid offered by the formal network.

Little attention has been paid to old people as support providers to their family [14]. However, an old person can be a caregiver even when health problems arise [15]. This enables him or her to continue to play a positive role within the family by maintaining a principle of reciprocity in exchange of services. The ability to provide various types of support may vary over time with increasing levels of impairment. Thus, the range of services that ADL-dependent persons can give to those around them is severely curtailed [2, 21]. To our knowledge very few studies have investigated whether readjustments of this kind have already begun among very old persons with a less deteriorated health status.

Addressing the issue of support among octogenarians reporting frailty, a leading and lasting health situation in very old age [7], is particularly relevant because frail individuals are at higher risks of becoming ADL-dependent. Frailty is conceptualized as a multi-system reduction in reserve capacity. As a consequence, the ability of the frail elderly to tolerate disturbing events is affected [19]. The frail persons may need increased support from their family and their formal network to face disturbing events but also may have fewer resources to care for their family.

The capacity to provide services to others gives a positive role to any person, particularly to the aging persons. Our hypothesis is that elders will try to maintain this role as long as possible even when they require help from others. Thus, this study considers

the very old persons as support providers as much as support recipients. Our main objectives in this article are a) to evaluate whether the amount of instrumental support received by the very old persons from their family and formal networks is linked to their health status, b) to assess in which extent frail persons and ADL-dependent persons still help their family, and c) to identify the socio-demographic factors that influence the support provided and received in advanced old age.

## Methods

### Participants

The Swiss Interdisciplinary Longitudinal Study on the Oldest Old (SWILSOO) is a study involving sociology, social medicine, social and cognitive psychology, and econometrics [5, 8, 16]. The initial sample included 340 community-dwelling persons aged between 80 and 84 years. Participants were randomly selected from the list of registered octogenarians of the State Offices of Population living in the canton of Geneva (urban area) and in the central Valais (semi-rural area) in Switzerland. The sampling frame was stratified by geographical area and gender, and samples of equal size were drawn from each stratum. Each octogenarian answered to a trained interviewer, either in person or, if not able, through the intermediary of a proxy (the frequency of proxy reports ranged from 13.2% to 23.3% throughout the study period). We considered here the first five waves of assessment from 1994 to 1999 (separated by 18, 12, 12, 18 months), and focused on community-dwelling participants which totalled 1153 interviews across the five waves (Table 1). Institutional-dwelling participants were not asked about their social support and were consequently excluded from the analysis. After five years of the study, 168 (49.4%) participants had dropped out of the survey, among whom 111 had died, 7 had moved to a different area. The remaining participants had left the study because of health problems or lack of interest in the survey. Older ages, lower physical health status, and lower socio-economic status characterized the participants who dropped out of the survey [6].

**Table 1** Number of interviews for community and institutional-dwelling participants and attrition across the five waves of SWILSOO

Wave	Interval between waves (month)	Total sample	Community-dwelling participants (self-respondents only)	Institutional-dwelling participants (self-respondents only)	Drop out (deceased only)
W1	–	340	340 (295)	0 (0)	–
W2	12	267	251 (224)	16 (6)	73 (28)
W3	18	237	219 (190)	18 (7)	30 (21)
W4	18	209	190 (162)	19 (9)	28 (26)
W5	12	172	153 (124)	19 (8)	37 (36)
W1–W5		1225	1153 (995)	72 (30)	168 (111)

## Measures

Two series of questions assessed the frequency of instrumental aids that the very old person provided<sup>1</sup> or received<sup>2</sup> from non-household family members. A choice of four possible answers was offered: “never”, “rarely”, “sometimes”, and “often”. For services provided by the participants, only those who were able to answer in person were questioned (N=295 persons at baseline; 995 interviews). These respondents were more likely to be younger and to be in better functional health than the proxy respondents excluded, who otherwise were similar by gender. For services received from non-household family members, all home-dwelling participants were questioned (proxy respondents were excluded at baseline; N=295 persons at baseline; 1108 interviews). For the formal network, a series of seven aids<sup>3</sup> was proposed to all home-dwelling participants (N=340 participants at baseline; 1153 interviews) with six possible answers: “never”, “rarely”, “every month”, “every two weeks”, “once a week”, “every day”. Those questions enabled us to construct frequency scores for each of the three types of social support by averaging out the different answers given.

ADL-dependence was assessed by the standard instrument of Katz et al. [9], which includes washing, dressing and undressing, eating, rising from and going to bed, and moving around the living

quarters. A participant was considered ADL-dependent if he/she was unable to perform alone at least one of these five activities. Frailty was operationalized on the basis of two or more deficiencies in five health domains: sensoriality, mobility, memory, energy, and physical ailments. Previous analyses from the SWILSOO showed that very old persons affected by deficiencies in two different domains were at increased risk of developing ADL-dependence in the next 12 to 18 months to come and of dying within the next five-year period. The ADL were combined with the frailty indicator to obtain a health status in three categories: ADL-dependent frail (denoted as ADL-dependent), ADL-independent frail, and ADL-independent non-frail (i.e. robust). The fourth combination describing the non-frail but ADL-dependent individuals was very rare (less than 1% of the sample). It was verified that this combination was highly unstable, and in subsequent analyses these individuals were considered ADL-dependent (for further details, see [7]).

The family network was assessed by standard questions about household composition (living alone or not), the existence of living siblings and descendants (children, grand-children or great grand-children).

The socio-demographic variables used in the present study included age, gender, geographical area (urban or semi-rural area) and socio-economic status (working-class or middle/upper-class). Socio-economic status was assessed as a composite of education, income and socio-professional categories.

## Plan of analysis

The objective was to investigate the effects of participants' health status on the repeated measures of 1) services provided by the very old participants, 2) services received from family network and 3) services received from formal network, controlling for socio-demographic variables and family network variables, using multilevel analyses. Multilevel ana-

<sup>1</sup> Seven services have been taken into account: 1) performing household tasks, bringing or preparing meals; 2) doing the shopping; 3) repairing items, doing odd jobs, gardening; 4) making clothes or other items; 5) taking a member of the family for a walk or to a show, a café or a restaurant; 6) helping a member of the family in his or her occupational activities; 7) looking after the children, seeing that they do their homework.

<sup>2</sup> Six services have been taken into account: 1) performing household tasks; 2) bringing or preparing meals; 3) doing the shopping; 4) repairing items, doing odd jobs, gardening; 5) helping with completing income tax return, declarations for insurance purposes; 6) helping with toilet activities (taking a bath, doing hair).

<sup>3</sup> 1) nurse, 2) household/family helper, 3) physiotherapeutic/ergotherapeutic services, 4) social worker, 5) meals on wheels, 6) day-care centres, 7) membership of an association.

lyses have been developed for the purpose of analysing data with multilevel sets (e.g. repeated measures within an individual). They allow the use of repeated measures where both the number of interviews per participant and the time intervals between interviews vary. Furthermore, multilevel analyses can tolerate an incomplete data set because they use all available data instead of restricting the analysis to individuals who participated to the five waves of follow-up [4] and therefore limit the selectivity effects.

The three models mentioned below used up to five waves of assessment. Age (centered on its grand mean), health status, household composition and the presence of descendant were included as level-1, time-varying predictor, and gender, socio-economic status, and geographical area as level-2, time-invariant predictors. The variable 'geographical area' was considered as time-invariant because participants who moved outside the two sampled areas were excluded from the survey. Also examined were all possible interaction effects. Results were reported with a robust estimation of the standard errors and the effects were tested by the method of restricted maximum likelihood using HLM version 6 [17].

The three models (i.e. changes in the frequency of services provided and received from family and formal network) were divided into three steps. First, models included socio-demographic variables and health status (ADL-independent frail as the reference). Second, we added separately the family network variables and interactions between socio-demographic variables, as well as interactions between socio-demographic variables and health status. Third, the variables or interactions found to be significantly related to frequency of support in the second step were considered in subsequent multivariate modelling.

## Results

Although 40% of the participants were living alone at baseline, the family networks of the very old were rich in numbers: 80% of the participants had at least one living descendant (child, grandchild or great-grandchild) and 71% had still at least one living brother or sister (Table 2). The mean age (SD) of the participants was 81.9 (1.4) at study inception and 86.6 (1.4) five years later. During the five-year follow-up, the proportion of robust individuals decreased from 37% to 31% while that of ADL-dependent subjects increased from 12% to 21%. The proportion of ADL-independent frail individuals remained stable at around 50%. This ADL-independent frail category represented hence the leading health

status over five years in our sample and could be interpreted as a "buffer" category between robustness and ADL-dependence. During the same time period, the exchanges of services between the participants and their family largely evolved. At baseline almost half of the persons, notwithstanding their advanced ages, were providing at least one service to their non-household family members and half were receiving at least one service from their family. Five years later one-third was still a provider of services, and about two-thirds were care recipients. Aid from the formal network was used less than aid from the family. At study inception, 29% of the participants were receiving at least one service from the formal network, and during the study this aid increased and reached 47% of the interviewed persons.

The frequency of services that the participants received from their family networks was gradually related to their health status: robust individuals received less frequent support (regression coefficient,  $\beta$  (Standard Error, SE) = -0.10 (0.04)\*) and ADL-dependent individuals more frequent support ( $\beta$  (SE) = 0.16 (0.07)\*) compared to ADL-independent frail subjects (Table 3).

**Table 2** Characteristics of home-dwelling participants at baseline and five years later: number (%) (or mean (SD) when specified)

Domain	Characteristics	Baseline (N = 340)	Five years later (N = 153)
Socio-demographic	Age (years), mean (SD)	81.9 (1.4)	86.6 (1.4)
	Gender: woman	168 (49)	81 (53)
	Socio-economic status: middle/upper-class	139 (41)	66 (43)
	Geographical area: urban	173 (51)	68 (44)
Health status	Robust	127 (37)	47 (31)
	ADL-independent frail	172 (51)	73 (48)
	ADL-dependent	40 (12)	33 (21)
Family networks	Lives alone	132 (40)	70 (46)
	Has at least one descendant	271 (80)	130 (85)
	Has at least one sibling	241 (71)	104 (68)
Exchanges of services with family	Provides at least one service	123 (44)	39 (32)
	Receives at least one service	143 (51)	96 (64)
Services received from formal network	Receives at least one service	96 (29)	71 (47)

At baseline, only participants able to answer in person were considered for exchanges of services with family (N=295); five years later, only participants able to answer in person were considered for provided services (N=124); percentages are given for subjects without missing values



**Table 3** Effects (regression coefficient (standard error)) of potential determinants on the average frequency of services 1) provided by the very old persons to their family network, 2) received from their family network, and 3) received from formal network.

Domain	Characteristics	Family network		Formal network
		Services provided (N = 995 interviews)	Services received (N = 1108 interviews)	Services received (N = 1153 interviews)
Socio-demographic	Age (years)	-0.05 (0.01)***	0.00 (0.01)	0.03 (0.01)***
	Gender (woman)	0.03 (0.03)	0.06 (0.06)	-0.01 (0.05)
	Socio-economic status (middle/upper-class)	0.06 (0.03)	-0.09 (0.04)*	0.09 (0.06)
Health status	Geographical area (urban)	-0.10 (0.03)**	-0.22 (0.05)***	0.18 (0.07)**
	Robust vs ADL-independent frail	0.05 (0.03)	-0.10 (0.04)*	-0.06 (0.03)*
	ADL-dependent vs ADL-independent frail	-0.09 (0.03)**	0.16 (0.07)*	0.46 (0.06)***
Family networks	Lives alone	/	0.15 (0.05)**	0.16 (0.05)**
	Has at least one descendent	0.12 (0.03)***	0.29 (0.04)***	/
Interactions	Age × geographical area	0.03 (0.01)*	/	/
	Robust × gender	/	0.08 (0.06)	/
	Socio-economic status × geographical area	/	/	-0.23 (0.09)**

\*p<0.05; \*\*p<0.01; \*\*\*p<0.001; / variables not included in multivariate modelling because of their non significant effects in univariate modelling

The provision of services by the very old person was also altered by his/her health, but in a nonlinear form. The group of ADL-dependent persons stood apart from the other two health statuses in that they offered drastically less aid ( $\beta$  (SE) = -0.09 (0.03)\*\*). In contrast, the frequency of aid offered to the family was the same for both ADL-independent frail and robust persons ( $\beta$  (SE) = 0.05 (0.03)).

The use of institutional services depended primarily on the health status of the person concerned. Aid of this type was encountered much more frequently among ADL-dependent persons than among ADL-independent frail persons, who in turn received more than robust persons ( $\beta$  (SE) = 0.46 (0.06)\*\*\* for ADL-dependent vs ADL-independent frail;  $\beta$  (SE) = -0.06 (0.03)\* for robust versus ADL-independent frail).

The health status of the elderly was not the only factor determining the frequency of exchanges of services with their entourage. For a given health status, the support provided by very old people diminished over the course of the five-year period ( $\beta$  (SE) = -0.05 (0.01)\*\*\*). In contrast, the services received by octogenarians from their families remained stable over the period. Logically, having one or more descendants substantially increased the frequency of the services which the persons provided to their families ( $\beta$  (SE) = 0.12 (0.03)\*\*\*) and received from their families ( $\beta$  (SE) = 0.29 (0.04)\*\*\*). Persons without a cohabitant – who, when present, is the principal caregiver – received more services from the rest of the family ( $\beta$  (SE) = 0.15 (0.05)\*\*) but provided services to their family with the same frequency as persons living with a cohabitant. The

region of residence was also a determining factor in exchanges of services with the family network; persons living in the urban area received fewer services ( $\beta$  (SE) = -0.22 (0.05)\*\*\*) and gave fewer ( $\beta$  (SE) = -0.10 (0.03)\*\*). In addition, persons in the middle or upper socio-economic status received fewer services from their families ( $\beta$  (SE) = -0.09 (0.04)\*).

The frequency of aid provided by the formal network was higher for the oldest members of our cohort ( $\beta$  (SE) = 0.03 (0.01)\*\*\*). Persons living alone had more frequent recourse to formal aid ( $\beta$  (SE) = 0.16 (0.05)\*\*) irrespective of whether or not they were in a family network. Living in the urban area – where the supply is greater – made for use of formal services ( $\beta$  (SE) = 0.18 (0.07)\*\*). In this region the persons of middle or higher socio-economic status received less formal aid ( $\beta$  (SE) = -0.23 (0.09)\*\*) than persons in lower socio-economic categories, while in the semi-rural zone socio-economic status had the inverse effect on the amount of formal aid received.

## Discussion

In term of health, each category of persons – robust, ADL-independent frail and ADL-dependent – received different levels of aid, and we have shown here that aid goes to those who need it most. While the recourse to the family network increased progressively with the process of frailty, the recourse to the formal network drastically increased for ADL-dependent individuals.

With regard to geographical area effects, exchanges of services with the family are less frequent in the urban region; but formal aid, which is more developed there, is used more than in the semi rural area. In an urban context a pattern of organization of daily life can be observed which is based on delegation of part of domestic chores to paid personnel, whereas in the Alpine region these tasks are performed by relatives [12]. Surprisingly, in the semi rural area, persons of low socio-economic status use institutional aids less frequently than persons of middle/upper socio-economic status. One explanation could be that persons of low socio-economic status of the central Valais are rather living in distant and isolated villages accessible with difficulty, particularly in winter, to formal aids.

Another finding of this study, about which relatively little appears in the literature, relates to the caregiver activity of very old people. At baseline, 44% of the participants provided services to their non-household family members. This challenges the assumption that informal caregivers are overwhelmingly middle-aged people. The level of this support was seriously affected for ADL-dependent persons. This coincides with other results obtained by Van Tilburg and Broese Van Groenou [21], which demonstrated that decline in functional ability predicted a decrease in instrumental support provided. Studies in the field of intergenerational exchanges show that old persons do not necessarily feel this affected capacity to give services as a debt on the grounds that the services they are currently receiving may make up for the many services they have provided in the past [21]. Some studies suggest that old people, when too afflicted by health problems to give ser-

vices, endeavours to make up for that shortcoming by greater emotional support [18, 20].

In contrast, ADL-independent frail persons were caregivers with the same frequency as the robust oldest old. The ADL-independent frail elderly people in our sample maintained the give and take of support in their relationships, even through some types of support provision may become increasingly difficult to accomplish. Qualitative interviews with a subset of participants of the SWILSOO showed that there was a decrease in some types of services but those supports were compensated by other help that can still be performed. The ability to maintain certain levels of support provision when a person is ADL-independent frail may also be influenced by the recourse to the formal network. The latter can help frail people to save time and resources, and can allow them to still give services to their family [1, 11]. The ability to reciprocate the support that older persons receive from their family networks enables them to continue to play a positive role within their family. This continuity of roles may in turn impact positively the well-being of an aged parent [2, 10]. Reciprocating support was indeed found to be associated with satisfaction, happiness, and self-esteem [13].

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